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Living with suicidality following traumatic brain injury: A qualitative study

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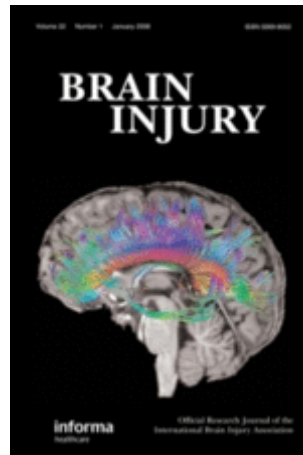
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Living with suicidality following traumatic brain injury: A qualitative study

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Abstract

Purpose: Numbers of traumatic brain injury (TBI) are increasing, and with suicidality post-injury presenting at 3-4 times higher than in the general population, understanding this is crucial in reducing a devastating outcome. Given the lack of literature, this study investigated the experiences of living with suicidality after TBI.

Methods: Interview data from nineteen ~~TBI~~ participants with TBI from a Brain Injury Rehabilitation Unit (BIRU) in New South Wales (NSW), Australia ~~were~~ collected and thematically analysed.

Findings: The participants (predominantly male) had sustained extremely severe injuries (median PTA 60 [IQR 81.0] days) and were in the chronic phase post-injury (median 8.0 [IQR 9.0] years). Six main themes were identified; Loss of sense of self, TBI as a hidden disability, Chronic but transient suicidality, Reliance, Protective factors, and Hope. Tentative relationships between themes and subthemes were identified.

Conclusion: Chronic suicidality after TBI was demonstrated consistently regardless of receiving long-term support. However, their engagement with protective factors such as social support, spirituality and positive personal qualities was also identified. Implementing these as coping strategies during long-term rehabilitation may reduce the levels of suicidal distress. Implications, methodological considerations and future research were discussed, with the aim of improving experiences of individuals with TBI to reduce suicidality.

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Keywords: Traumatic Brain Injury; Suicide; Suicide ideation; Hopelessness; Lived experience; Protective factors

For Peer Review Only

2
3 **Introduction**
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5 Traumatic Brain Injury is the leading cause of death and disability in children
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7 and adults under the age of 40 (1). Recent statistics from New South Wales,
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9 Australia report an incidence rate of 150 per 100,000 for TBIs (2). While some
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11 individuals presenting with TBIs may make a full recovery, many require extensive
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13 rehabilitativeen services and require long-term support to manage the physical,
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15 cognitive, behavioural, and emotional difficulties associated with TBI (3).
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21 The factors above lead to wide-reaching psychosocial impacts on individuals.
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23 Cognitive impairments make long-term reintegration problematic in terms of social
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25 integration and return to work or education (4), with return to work rates as low as
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27 30% two years post-injury (5, 6). The relationship between TBI and mental health is
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29 also complex, with individuals showing greater risk for developing anxiety and
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31 depression post-injury, but also with pre-existing mental health conditions acting as
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33 an increased risk factor for TBI (7). The cognitive difficulties coupled with the
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35 emotional and behavioural changes can lead to a multitude of long-term community
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37 integration issues for individuals with TBI, and highlights the impact that TBI can
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39 have on quality of life (6). High levels of social isolation have been implicated in the
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41 development of depression (not associated with changes in brain mechanisms),
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43 feelings of loss of sense of self, and low self-esteem (7, 8). Substance misuse
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45 among individuals is also high, with as many as 60% engaging in drug or alcohol use
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47 post-injury (9). An estimated 46% of these develop substance misuse difficulties with
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49 no prior pre-morbidity (10). Individuals with TBI have also been found to be 3-4 times
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51 more likely to take their own lives (11-13). These rates can remain constant for up to
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25 years post-injury, but pinpointing a period of elevated risk has been challenging (14).

Research found that substance misuse, psychiatric disturbances and hopelessness were common risk factors of suicidality after TBI. Whilst immediately after TBI substance use decreases (15), consumption post-injury tends to increase beyond pre-injury levels (16) and has been associated with increased suicidality (14). Further to this, comorbid post-injury psychiatric history and substance misuse, increased suicidality by 21 times compared to those with no history (17). Individuals with TBI often show significant rates of pre-injury psychiatric history with depression rates between 25%-33% (18). This suggests that prior comorbid disorders may accelerate suicidality merely by contributing to the post-injury risk factors. Finally, individuals with TBI express an increased sense of burden and high levels of hopelessness on their social network (19). Hopelessness was found to be a strong, independent predictor of suicidal ideation post-injury, and thus suicidality (17, 20).

Interviews with veterans with TBI found that social support, hope and religion/spirituality were common protective factors after TBI (19). Therefore, understanding protective factors among the TBI population may guide interventions to reduce suicidal behaviours. A study (17) identified that 26.2% of ~~TBI~~ outpatients with TBI had made at least one suicide attempt, with 44.2% of this sample making repeated attempts. The majority (70%) of attempts from these individuals were made post-injury, demonstrating that understanding their experiences of suicidality after TBI was vital in targeting their triggers and using their protective factors to guide future interventions.

Whilst the literature on suicidality after TBI continues to grow (11, 12), there is currently a lack of qualitative research in this domain to help understand the lived

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experience of suicidality after TBI. To the best of our knowledge, the only study published to date explored the experiences of suicidality within a small sample of military veterans with TBI (19). However, no studies have been conducted looking at a civilian population. Therefore, this study aims to explore the lived experiences of suicidality in a wider population of civilians with severe TBI.

Methods

Participants

Twenty individuals living with chronic suicidality after TBI participated in the present study. However, one of the interview tapes malfunctioned so it was removed before analysis and from the demographic information. All individuals were active clients of the Liverpool Hospital Brain Injury Rehabilitation Unit New South Wales (LH BIRU, NSW). Review of the medical records and information elicited directly from the clients indicated that no participant in the study had sustained their injury as the result of a suicide attempt. Inclusion criteria were: Experienced a traumatic brain injury after the age of 18 years; currently aged between 18-65 years; not currently having an acute psychiatric illness; sufficient cognitive and communication capacity to participate in a semi-structured interview; sufficient fluency in English; and more than 1-year post-TBI. Ethical clearance was gained from South Western Sydney Local Health District Human Research Ethics Committee and the Faculty of health and Human Sciences, University of Plymouth.

Data collection

Qualitative information was collected using a semi-structured interview, developed by the third author. The schedule consisted of five open-ended questions. These

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questions explored post-TBI challenges, coping strategies, experiences of suicidality, protective factors, and current/ future hopes. Participants were recruited by the third author LH BIRU as part of a larger study addressing the effects of TBI on emotions and suicidality. One-hundred and seventy-two clients receiving support from this BIRU were screened and a subset identified as having attempted suicide after TBI. The first twenty clients who reported this, and met the inclusion criteria, were invited to participate.

A data protocol was employed to collect information on demographics, injury characteristics, alcohol and drug use as well as any psychiatric diagnosis. None of the clients declined participation and interviews were conducted face-to-face between September 1999 and May 2000, either at LH or at the client's home. Interviews took between 30-45 minutes to conduct and all participants had sufficient capacity to provide informed consent, as determined by the LH BIRU treating rehabilitation physician and neuropsychologist.

As suicidality was the main topic, a protocol was in place to avoid unnecessary psychological harm. If a client started to display distress, the interview would be paused to allow them time to compose, and checks conducted to see if they wanted to continue. If a client became extremely distressed the interview would be terminated immediately and an urgent appointment booked with the Clinical Psychologist. None of these eventualities arose and all participants were receiving the standard rehabilitation from the LH BIRU community multidisciplinary rehabilitation team throughout.

Data Analysis

Analysis of data was guided by the six phases of thematic analysis (TA; see below) (21). Interviews were analysed separately, in the order of which they were

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conducted and transcripts named accordingly (C1, C2... etc). To ensure privacy, prior to data sharing, interviews were transcribed and identifying information (e.g., names of agencies, staff members, and so forth) were encoded using combinations of letters (e.g. AAAA). These were used consistently throughout each transcript to refer to the same person/ agency, but across transcripts letters were recycled. A descriptor was added in parenthesis to clarify the type of person/ agency.

TA is commonly used in qualitative research to study individuals with TBI populations (22, 23). It was selected because it is accessible and flexible in gaining meaningful, rich, intricate details that are directly reflected in the participants' language (21). A semi-structured interview was used because it suited the parameter of achieving a variety of individualised experiences about living with suicidality after TBI, compared to a structured interview or questionnaire (24).

Stage ~~s~~ one of the analyses involved reading the transcripts thoroughly, while noting down potential items of interest to enable familiarisation with the participants' experience. This was repeated several times until a comprehensive~~complex~~ understanding of everyone's experiences was established (Stage two). Stage three focused on generating a set of initial codes, eventually assigning complete codes across the entire dataset that related to living with suicidality after TBI. Great care was taken to ensure that codes and themes were in line with participants' use of language and culture. Stage four consisted of identifying similar and overlapping codes to develop potential themes and several emerged, capturing central organising concepts within and across the dataset.

In Stage five, the first author produced a thematic map (Figure 1) to provide a visual representation of the relationships between different themes (main concepts within the dataset), and sub-themes (different concepts related to each main theme).

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Finally, these themes were clearly named and defined to express their meanings and implications, and then the analysis was verified by the second and third authors (stage six). Themes are discussed in the 'Analysis' section and an integrative approach of literature was used to fully develop the link between theory, research and practice (21).

Qualitative analysis is subjective in nature and the first author conducted the analysis viewed through her experience of working collaboratively with individuals living with TBI and their families in the UK. The first author notes that she had limited clinical experience of working with suicidality. Support to consider this aspect of the dataset was provided by the second and third authors who both have clinical experience of working with participants with TBI ~~participants~~ who are suicidal. The third author also provided ~~and~~ knowledge about the cultural and systematic differences between the UK population and those from NSW.

Results

The demographic/injury (Table 1), psychosocial (Table 2) and clinical (Table 3) characteristics of the TBI participants were collated and summarised. The analysis of the interviews revealed six main themes: Loss of sense of self, Reliance, TBI as a hidden disability, Chronic but transient suicidality, Protective factors and Hope (Figure 1).

Insert Tables 1-3

Insert Figure 1

Theme 1: Loss of Sense of Self

This theme captured the conscious awareness individuals had in understanding they were no longer the person they were prior to their injury, with

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many comparing their pre-injury and post-injury skills and abilities. C1 stated “*not being able to do the sorts of things that I used to be able to do*” (Male, 9-years post-injury) made him feel distressed after his injury. Some participants also compared their post-injury abilities with abilities of non-TBI individuals. C17 recalled, “*all me mates, married and they’re all dads, mentally dads. But I’m not mentally a dad*” (Male, 19-years post-injury). This extract suggested an aspect of grieving for his pre-injury life because he perceived that his friends, who were in similar familial situations, were better functioning.

Sub-theme: Changes in employment. A subtheme that encompassed the positive and negative responses of either resuming employment or not, after injury. One participant, who had the ability to return to work compared his life with and without employment, “*before I started work again I thought I’d never be good for anything*” (C2, Male, 14-years post-injury). It highlights the positive role returning to work can play in an individual’s self-worth by restoring a sense of purpose. In individuals who were unable to return to work, this provoked frustration because the workplace often provides a good source of support and social interaction, C18: “*I lost contact with all the friends I’d made through work ... had a lot of friends*” (Male, 4-years post-injury). Not being able to return to work negatively impacted this individual’s interpersonal relationships with his colleagues because the continuity of ‘*support from social network*’ was not maintained (see Theme two).

Sub-theme: Long-term Effects of TBI. This subtheme depicted the long-term physical and cognitive manifestations that can occur after injury, which many found hindered their functioning. Several participants reported having difficulties with their cognitive abilities, and for C10 it interfered with work, “*I couldn’t hold the information in, I’d have to wait until everyone went out and then write*

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everything down" (Male, 1-year post-injury). Mobility was also frequently identified by participants as being affected post-injury. C8 reported "*just finding out my physical abilities, plus my physique is not as good as it used to be*" (Male, 5-years post-injury). This individual acknowledged his new physical identity, understanding that the TBI had changed his 'old' appearance.

Theme 2: Reliance.

This overarching theme explained how participants with TBI ~~participants~~ have coped after encountering negative thoughts post-injury and can be linked divided into two different domains; reliance on self and reliance on others.

Self: The participants in the study identified relying on themselves to cope with the negative effects after their injury. Positive coping strategies taught by professionals, were self-initiated when negative thoughts occurred. C18 explained "*I try and write something on the computer, it gave me chance to understand a bit better what was going on.*" This individual actively confronted the negative thoughts he was experiencing about his injury. Self-reliance was associated with two subthemes; distractions and risky behaviour.

Sub-theme: Distractions. Preventing concentration on negative thoughts could be viewed as both a positive and a negative way to cope after TBI. Positive distracting strategies involved conducting activities that were unrelated and not affected by the injury, "*I have to read a lot to keep my mind away from bad thinking*" (C13, Male, 6-years post-injury). However, many individuals also engaged in negative distracting techniques such as active avoidance of their injury and its associated effects. C11 stated he "*just slept as much as [he] could, try and switch off*" (Male, 8-years post-injury). Whilst this participant inferred avoidance helped subside

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negativity, it was only a temporary solution for a larger problem, because the underlying cause was not dealt with.

Sub-theme: Risky behaviours. This sub-theme captured substance misuse behaviours that potentially exposed participants to harm but were used as a coping strategy to reduce negative thoughts. For example, C2 reported that “*with marijuana it made the sadness go away but with the alcohol it brought it on more*”. Participants also recognised that whilst substances mellowed negative thoughts, they can initiate serious problems if risky behaviours continue, “*it takes away one problem but it gives you another*” (C3, Male, 6-years post-injury). This individual suggested that substances displaced his negative thoughts, but he understood that long-term use could lead to dependency.

Reliance on others: As well as self-reliance, participants talked about their reliance on others for support to cope with the negative effects of their injury. Whilst C10 stated “*certain people*” provided positive emotional support, it also implies that support was not consistently offered by all people. Support from others was associated with two sub-themes of support from social network and support from professionals.

Sub-theme: Support from social network. This described the availability of support given by participants’ family, friends and the community to reduce negative thoughts after injury. Participants expressed their gratitude towards family members throughout their recovery, C20 emphasised that “*mum and dad used to give me a lot of encouragement to go on in life*” (Female, 29-years post-injury). This individual’s family offered high levels of support and motivation after injury. However, some participants felt guilty for frequently relying on their social network. C11 specified: “*he’s flat out doing what he’s doing without worrying what’s going*

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on in my life". This implies participants feel like they are imposing on and limiting another's life.

Sub-theme: Support from professionals. The sub-theme highlights both the positive and negative experiences participants encountered with healthcare professionals. Some participants found conversing with trained staff helpful in improving their insight. C2 stated: *'I used to talk to CCCC (staff member) when I was at DDDD (community brain injury service) ... if I had any problems I used to go back'*. This inferred the guidance and teaching from professionals in the community was gratefully received because C2 felt able to return. Conversely, inexperienced professionals can hinder recovery for participants. For example, C16 declared *"it would generate more bad feelings ... they were badly trained on how to deal with..."* (Male, 14-years post-injury). This individual found support from professional staff unhelpful because it increased his negative ideation.

Theme 3: TBI is a hidden disability. This theme describes the hidden appearances of psychological, cognitive, social, and emotional problems, whilst appearing physically 'intact' to other people. It is often assumed that a disability is characterised by visibility, however C15 argued *"I'm a broken product, I got two legs and two arms - I should be able to do things but I can't make 'em work"* (Male, 9-years post-injury). It revolves around this misconception that individuals have suddenly 'recovered' once they have regained their physical abilities, yet their psychological difficulties tend to persist. This was linked to the theme of loss of sense of self and the long-term effects of TBI (see Theme 1). It was highlighted as something that some professionals failed to appreciate, and that the general population did not necessarily understand. This theme was also linked to the sub-theme of poor knowledge of TBI.

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Sub-theme: Poor knowledge of TBI. Participants noted the poor level of awareness the general population had surrounding TBI. C4 stated “*people treated me like I was brain damaged*” (Male, 7-years post-injury). This individual suggested he felt he was treated differently to non-injured people because others did not understand or have experience with TBIs. Further to this, participants also felt socially excluded by other people, for example: C14 stated “[*they*] *don’t notice you ... and you don’t exist*” (Male, 11-years post-injury). This extract highlights that if people do not have knowledge about TBI, they are unable to provide adequate support, leading to feelings of alienation and social isolation.

Theme 4: Chronic but transient suicidality

The participants in this study described living with suicidality and persistent negative thoughts. Seemingly, suicidality occurs over a long period of time, C17: “*it’s always there*”, which can be heightened or reduced by situations, C5: “*it’s a wave, all of a sudden you wake up one morning, snap out of it*” (Male, 1-year post-injury).

~~These experiences are akin to a sine wave.~~ The peaks and troughs in experiencing suicidality represent events that increase and decrease suicidality over the course of one’s lifetime, with events affecting each individual differently. It is important to note though that even in the troughs, participants were experiencing persistent negative thoughts and suicide ideation but they were not necessarily considering acting on these thoughts. This theme was associated with three sub-themes; triggers heighten suicidality, feeling trapped, and poor self-worth.

Sub-theme: Triggers heighten suicidality. This sub-theme highlights specific situations that increase sensitivity to suicidality after TBI. Although some individuals found it difficult to identify triggers, pain and stressful life events, these were frequently reported as contributing factors. C19 reported waking up “*with the same*

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pain ... I'm going through day after day..." (Male, 1-year post-injury). This participant, alongside many others, reported that living in constant pain was a battle because it hindered all aspects of one's life. Moreover, stressful changes to an individual's life, especially when the outcome is negative, can act as a trigger. For example, C20 reported high suicidality after her father died, "*I couldn't take it*". This individual's father played a large supportive role during her recovery. However, his passing acted as an aversive life event.

Sub-theme: Feeling trapped. This sub-theme helps to explain why the TBI participants who engaged in suicidal behaviours, do not actually take their own lives. A commonality across participants was their perception of not having the ability to complete suicide, specifically in having limited resources or being too scared.

"C8: *I'm scared of dying ... just the pain.*"

"C13: *I don't have the means to do it, I always thought if I had a gun...*"

Although both participants expressed the desire to die, the acquired ability to enact lethal self-injury was not always possible, in part to the physical injuries that individuals had received as a result of their TBI. This led to participants feeling trapped and unable to enact their suicidal ideations.

Subtheme: Poor self-worth. When participants were asked about 'positive personal attributes', they found it difficult to identify these qualities. Instead, many discussed negative aspects they perceived about themselves. C6 reported feeling "*bad in myself*" (Male, 17-years post-injury), whilst C13 added "*I feel worthless*". This low self-worth may be intrinsically linked to their suicidality and where participants were able to express these, this seemed to serve as a protective factor (see Theme 5).

Theme 5: Protective factors

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This theme encapsulated the reasons identified by participants with TBI that contributed to reductions in their suicidality and was linked to three sub-themes; perceived sense of other's loss, positive personal attributes and spirituality.

Sub-theme: Perceived sense of other's loss. In the interviews, participants often understood that their social network would be negatively affected if they took their own lives. When asked about their protective factors, family was repeatedly brought up. This linked with reliance on others; this increased reliance had forged strong familial bonds that participants were ambivalent about breaking through suicide. C12 stated "*Just people around me*" (Male, 15-years post-injury) prevented a successful attempt. In particular, a child's loss of a parent through suicide was perceived worse among participants, than a family's loss more generally. C5 recalled "*I couldn't do it when she [daughter] was around because she would've known I was gone and that was the worst one.*" This suggests that the e-will to live was always greater than the will to die, because the guilt of leaving a child without support was overwhelming.

Sub-theme: Positive personal attributes. When participants were able to identify positive qualities about themselves after injury, particularly around overcoming challenges arising from long-term effects of TBI, there was a lowered feeling of suicidality. The most common were;

- **Sense of humour.** C1: "*I can make jokes ... when people ask how are you going, I say by wheels.*"
- **Determination.** C8: "*It was so difficult trying to get on the bus and in the end its just easy to get a bus*".
- **Resilience.** C20: "*Well I'm made to persevere ... I push myself. Tell myself I had to do it*".
- **Acceptance.** C11: "*You've got to try and put it behind ya. Make the best of what you can in the predicament*".

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- **Empathy.** C18: *"Friend of mine got a brain injury 10 years ago and he did commit suicide ... so I can understand why"*.

Sub-theme: Spirituality. This subtheme captured the belief some participants had about the contribution of an 'external force' in reducing suicidality. It promoted the idea that everything in life happens for a reason and that 'something' gave them a greater reason to live than to die. For example, C7 reported *"God, might be saving me because it's not my time"* (Male, 8-years post-injury). This individual's religion enabled them to question their existence which seemingly reduced suicidality.

Spirituality, the sense of connection to a higher power, was also conveyed during challenging times after injury, C19 stated *"I basically got a tap on my shoulder, there wasn't anyone there (...) 'you're going to be able to cope with it, tomorrow's going to be a different day'. And it was."*

Theme 6: Hope

Participants expressed how their current and future hopes impacted on their level of suicidality, both positively and negatively and was associated with two sub-themes; hope as an 'abstract construct' and findings one's sense of self.

Sub-theme: Abstract construct. In the interviews, participants expressed difficulties with understanding the meaning of hope. For example, C3 declared *"I really don't know, that's a hard one"*, when asked about his hopes. This extract could be interpreted in a number of two ways. For example;-in some cases individuals seemed to struggle with the construct due to high levels of negative thinking, but for others the construct itself seemed to be confusing, perhaps due to the severity of their cognitive impairments post-injury. It is also possible that some individuals have learnt over time to focus on the present rather than focusing on long-term hopes.

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Sub-theme: Finding one's sense of self. This sub-theme encapsulated the positive future hopes of some participants. Many individuals hoped their journey through recovery would end in them regaining their '*loss of sense of self*' (*Theme 1*). C4 expressed that "*all the pieces will come together ... to meet a girl and have a job*". This individual recognised the importance of hope for oneself; recapturing the person they were before their injury or identifying who they wanted to be if that never occurred. C15 highlighted the importance of hope during the negative times in his life, "*I've never seen a situation where you have no hope*". This individual attributed part of his survival, to hope, and without it suicide was a likely outcome.

Discussion

The study identified six main themes and related sub-themes associated with suicidality in individuals with TBI. A loss of sense of self, the need to rely on others, the use of unhelpful self-reliance and the hidden disabilities associated with TBI were all factors that attributed to individuals' suicidality. Participants within the study talked about the 'chronic' nature of suicidality, that it was always present but that the feeling of wanting to act upon those thoughts was more 'transient' and linked to certain triggers and poor self-worth. Many participants identified that the inability to physically carry out the act was the only factor protecting them from suicide. Other protective factors included a sense of hope, being able to identify positive personal attributes, spirituality, and a desire to protect others from the sense of loss they would experience if the individual did take their own life.

Many of the themes identified in this particular study were also highlighted in the previous study of military veterans with TBI (19). In both studies a loss of sense

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of self were highlighted as was cognitive sequelae (identified in this study as 'hidden disability'). Further similarities were identified in terms of protective factors including a sense of purpose (positive personal attributes), social support and religion or spirituality. While the support services for veterans are different from those provided to the general public, the findings from these two studies suggest similar long-term outcomes.

Loss of self is common following injury as individuals struggle to come to terms with the fundamental differences between their past self and present functioning (25). It creates a gap which is often associated with negative self-perceptions (26), and low self-worth (27), as highlighted in the present study. This low self-worth fed into a need for self-reliance post-injury. Positive self-distraction techniques, including relaxation or reading, can relieve stress and increase emotional wellbeing by reducing ruminative self-focus (28). Conversely, it is well established that the use of alcohol and substances post-injury is a significant problem amongst individuals with TBI (9), even when there is no pre-morbid history (29). In these instances, the substance misuse is likely to exacerbate any previous feelings of suicidality (30).

Despite this need for self-reliance, many individuals post-injury find themselves relying heavily on those around them (31). Family support and motivation has previously been found to be a protective factor during periods of heightened suicidality (19) as supported by the findings of this study. It is important to strike a balance between involving social support networks to increase the sense of emotional support, whilst ensuring that individuals maintain a perceived sense of independence, as over-dependency and perceived burdensomeness play a pivotal role in the interpersonal-psychological theory of suicidal behaviour (32).

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The dependency on others is further exacerbated by a lack of community resources of support from health and social care professionals (33) due to a lack of knowledge of TBI among these professionals (34, 35). This is often associated with misconceptions that recovery merely surrounds physical rehabilitation (33). The more 'hidden' symptoms of TBI, such as cognitive and emotional disturbance are often poorly understood (20, 33), leading to increased likelihood of experiencing emotional distress (36). Family members and members of the public can also struggle to understand these 'hidden' symptoms (37) due to a lack of basic education by professionals (34, 38), which can lead to individuals isolating themselves because they feel misunderstood (7). This may further exacerbate the likelihood of suicidality.

An important finding from this study was the 'chronic' basis for suicidality. While the likelihood of suicidal attempts was transient in nature, the feeling of wishing to end one's life was chronic amongst participants. Previous literature has identified that even after accounting for suicidality risk factors (depression, burdensomeness, thwarted belongingness), TBI was robustly associated with lifetime suicide risk (11, 14, 39, 40). Specific risk time-points seemed to be related to periods of particular low self-worth (31) and the presence of other specific triggers, such as stressful life events and chronic pain, which have previously been identified as critical predictors of suicidal ideation (41, 42).

Most worryingly was the finding that participants often did not go through with their suicidal ideations simply because they felt 'trapped' or unable to do so, rather than engagement with positive protective factors (43). The interpersonal-psychological theory of suicidal behaviour (44) suggests that suicide entails a fight with self-preservation motives, and when this battle is fought repeatedly in different domains, it instils the capacity to stare down this instinct. Repeated exposure to an

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aversive stimulus (e.g. pain), increases the likelihood that individuals will habituate to it (45).

When considering protective factors, this study highlighted that the perceived sense of other's loss can prevent suicide attempts, especially when children are involved (46, 47). Using personal strengths during difficult times has been found to improve self-worth within depressed and non-depressed TBI populations, leading to the reduction of suicidal ideations and attempts (48). This was accompanied by spiritual beliefs (religious or otherwise) that also provided strength to individuals when they were at their most distressed (49). This reflects research findings that spirituality is associated more broadly with positive outcomes after TBI including psychological coping, life satisfaction, and posttraumatic growth (50).

Return to work was highlighted as an important protective factor as it signifies a reduction in the burden on participants' social network and an increase in independence (19). An inability to return to work can elicit feelings of hopelessness, which is known to be a significant predictor of suicidality (20). Additionally, inability to return to work can exacerbate social exclusion which can contribute to poor psychosocial functioning and social isolation in individuals (51, 52).

Finally, hope was identified as important amongst participants, with hopefulness about the future being a protective factor in preventing future suicide attempts (53). Being able to integrate the still-present aspects of their 'old' identity with their 'new' self has been found to aid psychological recovery (54), increase life satisfaction (55) and reduce rates of depression and feelings of grief (27). Hope seemed to be linked to this integration process. However, for individuals living with suicidality after TBI, it is not uncommon for hope to be lost (56). The concept of hope

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seems to be difficult for some of the participants to grasp which may be associated with the severity of their TBI due to the ambiguous nature of the construct (57).

Strengths and Limitations

This study is the first to explore the lived experience of suicidality among those with TBI within the general civilian population. Participants within the study came from one single rehabilitation centre. The nature of qualitative research means that it is not intended to be generalisable, but the specific location makes it more difficult to draw any global conclusions from the findings of the study. Participants in the present study had access to consistent, long-term support following their TBI (2), whereas a gap in community service provision has been identified in many other populations (33). Comparing findings with other populations would enhance our understanding of the influence of short and long-term rehabilitation on suicidality in an effort to inform services for individuals with TBI.

Historical validity should also be considered; data for this study was collected in 1999-2000. Arguably, there has been little change in the service provision offered within New South Wales during this time period, but improvements have been made (2). Therefore, the present study should be interpreted with the knowledge that services provided to participants at the time may be somewhat different to those provided currently. Other wider social changes have also taken place that may influence adjustment in this population, such as the increased availability of online resources and social networks that may act as protective factors in the current time that were not available historically. An interesting future research study would be to compare this historic sample with data from a current cohort in areas where service

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provision has been identified as less comprehensive but where modern technology is available, such as the UK (33).

Most research has identified the psychologically-driven components of suicidality following TBI, such as depression, trauma, and loss of sense of self (8). However, suicidality could also be neurologically-driven; direct damage to areas such as the frontal and frontal-subcortical circuits can increase the risk of executive dysfunctions like impulsivity (58). Future research is still required to ascertain the respective influences of psychological and neurologically driven aspects of suicidality following TBI (41).

Implications and recommendations for practice

This study consisted of participants who all had access to long-term rehabilitation post-injury, including comprehensive care in the community. Yet despite this level of service, ~~the degree of~~ suicidality was prevalent in this reported in this cohort, as demonstrated by the themes extracted was high. This identifies a need for improved neurorehabilitation services worldwide to reduce the rate of suicidality. Some participants used risky behaviours such as substance misuse to manage their negative self-perceptions. Given that post-injury substance misuse can increase beyond pre-injury levels (16), individuals who elicit a higher risk should be offered long-term support. Early interventions focusing on the abstinence or management of substance misuse should be implemented into rehabilitation services (43).

Although many participants perceived the long-term support provided by professionals as positive, some also highlighted negative experiences. This stresses the importance of providing specialist TBI training to staff who work with this population (35) including tailored suicide prevention workshops (59). Every injury is different; thus, rehabilitation must be a person-centered, collaborative process,

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working towards improved functioning (33). Participants relied heavily upon their social network during periods of suicidality, but it was only perceived as supportive when they had TBI knowledge. This illustrates the need for educating families and friends, specifically about the hidden symptoms of TBI, and the role suicidality can play if long-term support is not provided (43).

In treating the pervasive hopelessness expressed by participants, the Window to Hope program is an important resource. The program is an evidence-based psychological intervention that has been proven in two randomised controlled trials as being effective in reducing chronic hopelessness after moderate to severe TBI (60, 61).

Participants identified chronic pain and stressful life events as the main triggers that increased their level of suicidality. Support services should help individuals to identify these key triggers and work with individuals to monitor suicidality long-term. As family and spiritual connections, as well as hope for the future were identified as protective factors, services should be focused on supporting families post-injury and helping to build positive coping strategies and social skills in the acute stages of rehabilitation.

Conclusion

This study aimed to explore the experiences of individuals with TBI living with suicidality. Interview data provided in-depth qualitative evidence of life after injury, emphasising the challenges they faced to develop a recursive relationship between TBI and suicidality. These findings highlight the profound impact TBI can have on an individual, and without sufficient long-term support or person-specific protective factors, suicidality may present. Developing an understanding into the complex

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interplay of this relationship could potentially inform community support services for those with TBI.

Declarations of Interest

The authors report no conflict of interests. This project was conducted as a part of a higher degree by research.

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References

1. Maas AR, Menon DK, Adelson PD, Andelic N, Bell MJ, Belli A, Bragge P, Brazinova A, Buki A, Chesnut RM, et al. Traumatic brain injury: integrated approaches to improve prevention, clinical care, and research. *Lancet Neurol.* 2017; [http://dx.doi.org/10.1016/S1474-4422\(17\)30371-X](http://dx.doi.org/10.1016/S1474-4422(17)30371-X)

2. New South Wales Agency for Clinical Innovation. *Brain injury rehabilitation directorate: Diagnostic report.* Available from: https://www.aci.health.nsw.gov.au/data/assets/pdf_file/0005/256712/Brain-Injury-Rehabilitation-Directorate-MOC-Diagnostic-Report.pdf [Accessed 15 March 2018]; 2014.

3. Barnes MP. Rehabilitation after traumatic brain injury. *Brit Med Bull.* 1999; 55(4): 927-943.

4. UKABIF. Acquired brain injury and neurerehabilitation time for change: All party parliamentary group on acquired brain injury report. Cornwall, UK: UKABIF; 2018.

5. Simpson GK, McRae P, Hallab L, Daher M, Strettles, B. Participation in competitive employment after severe traumatic brain injury: New employment versus return to previous (pre-injury) employment. *Neuropsychol Rehabil.* 2018; Nov: 1-18.

6. Van Velzen JM, van Bennekom CAM, Edelaar MJA, Sluiter MJ, Frings-Dresen MH. How many people return to work after acquired brain injury? A systematic review. *Brain Injury.* 2009; 23(6): 473-488.

Living with suicidality

7. Fleminger S, Ponsford J. Long term outcome after traumatic brain injury: More attention needs to be paid to neuropsychiatric functioning. *BMJ*. 2005; 331(7530): 1419-1420.
8. Whitnall L, McMillan TM, Murray GD, Teasdale GM. Disability in young people and adults after head injury: 5-7 year follow-up of a prospective cohort study. *J Neurol Neurosurg Psychiatry*. 2006; 77(5): 640-645.
9. Ponsford J, Whelan-Goodinson R, Bahar-Fuchs A. Alcohol and drug use following traumatic brain injury: A prospective study. *Brain Injury*. 2007; 21(13-14): 1385-1392.
10. Gould KR, Ponsford JL, Johnston L, Schönberger M. The nature, frequency and course of psychiatric disorders in the first year after traumatic brain injury: A prospective study. *Psychol Med*. 2011; 41(10): 2099-2109.
11. Madsen T, Erlangsen A, Orlovska S, Mofadd R, Nordentoft M, Benros ME. Association between traumatic brain injury and risk of suicide. *JAMA*. 2018; 320(6): 580-588.
12. Bahraini NH, Simpson GK, Brenner LA, Hoffberg AS, Schneider AL. Suicidal ideation and behaviours after traumatic brain injury: A systematic review. *Brain Impairment*. 2013; 14(1): 92-112.
13. Simpson G, Tate R. Suicidality in people surviving a traumatic brain injury: Prevalence, risk factors and implications for clinical management. *Brain Injury*. 2007; 21(13-14): 1335-1351.
14. Teasdale TW, Engberg AW. Suicide after traumatic brain injury: A population study. *J Neurol Neurosurg Psychiatry*. 2001; 71(4): 436-440.

Living with suicidality

15. Taylor LA, Kreutzer JS, Demm SR, Meade MA. Traumatic brain injury and substance abuse: A review and analysis of the literature. *Neuropsychol Rehabil.* 2003; 13 (1-2): 165-188.
16. Walker R, Hiller M, Staton M, Leukefeld CG. Head injury among drug abusers: An indicator of co-occurring problems. *J Psychoactive Drugs.* 2003; 35(3): 343-353.
17. Simpson G, Tate R. Clinical features of suicide attempts after traumatic brain injury. *J Nerv Ment Dis.* 2005; 193(10): 680-685.
18. Mainio A, Kyllönen T, Viilo K, Hakko H, Särkioja T, Räsänen P. Traumatic brain injury, psychiatric disorders and suicide: A population-based study of suicide victims during the years 1988-2004 in Northern Finland. *Brain Injury.* 2007; 21(8): 851-855.
19. Brenner LA, Homaifar BY, Adler LE, Wolfman JH, Kemp J. Suicidality and veterans with a history of traumatic brain injury: Precipitating events, protective factors, and prevention strategies. *Rehabil Psychol.* 2009; 54(4): 390-397.
20. Simpson G, Tate R. Suicidality after traumatic injury: Demographic, injury and clinical correlates. *Psychol Med.* 2002; 32(4): 687-697.
21. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006; 3(2): 77-101.
22. McRae P, Hallab L, Simpson G. Navigating employment pathways and supports following brain injury in Australia: Client perspectives. *Aust J Rehabil Counsel.* 2016; 22(2): 76-92.

Living with suicidality

23. Gracey F, Palmer S, Rous B, Psaila, K, Shaw K, O'Dell J, Cope J, Mohamed S. "Feeling part of things": Personal construction of self after brain injury. *Neuropsychol Rehabil*. 2008; 18 (5-6): 627-650.
24. Opdenakker RJG. Advantages and disadvantages of four interview techniques in qualitative research. *Forum: Qual Soc Res*. 2006; 7(4): 11.
25. Nochi M. "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Soc Sci Med*. 1998; 46(7): 869-878.
26. Judd DP, Wilson SL. Brain injury and identity: The role of counselling psychologists. *Counsel Psychol Rev*. 1999; 14(3): 4-16.
27. Carroll E, Coetzer R. Identity, grief and self-awareness after traumatic brain injury. *Neuropsychol Rehabil*. 2011; 21(3): 289-305.
28. Wylie GR, Flashman LA. Understanding the interplay between mild traumatic brain injury and cognitive fatigue: Models and treatments. *Concussion*. 2017; 2(4): CNC50.
29. Horner MD, Ferguson PL, Selassie AW, Labbate LA, Kniele K, Corrigan JD. Patterns of alcohol use 1 year after traumatic brain injury. A population-based, epidemiological study. *J Int Neuropsychol Soc*. 2005; 11(3): 322-330.
30. Essang M, Ahmed S. A closer look at substance use and suicide. *Am J Psy*. 2018; 6(1): 6-8.
31. Ponsford JL, Kelly A, Couchman G. Self-concept and self-esteem after acquired brain injury: A control group comparison. *Brain Injury*. 2014; 28(2): 146-154.
32. Joiner TE. *Why people die by suicide*. Cambridge, MA: Harvard University Press; 2005.

Living with suicidality

33. Odumuyiwa T, Kennedy M, Norman A, Holloway M, Suffield F, Forrest H, Dicks H. Improving access to social care services following Acquired Brain Injury: A needs analysis. *J Long Term Care*. 2019; 2019: 164-175.
34. Norman A, Holloway M, Odumuyiwa T, Kennedy M, Forrest H, Suffield F, Dicks H. Accepting what we do not know: A need to improve professional understanding of brain injury in the UK. *Health Soc Care Comm*. [Forthcoming \(in press\)](#)
35. Holloway M. How is ABI assessed and responded to in non-specialist settings? Is specialist education required for all social care professionals? *Social Care and Neurodisability*. 2014; 5(4): 201-213.
36. Gordon WA, Brown M, Sliwinski M, Hibbard MR, Patti N, Weiss MJ, Kalinsky R, Sheerer M. The enigma of "hidden" traumatic brain injury. *J Head Trauma Rehabil*. 1998; 13(6): 39-56.
37. Stevens PK, Penprase B, Kepros JP, Dunneback J. Parental recognition of postconcussive symptoms in children. *J Trauma Nurs*. 2010; 17(4): 178-182.
38. Linden MA, Braiden HJ, Miller S. Educational professionals' understanding of childhood traumatic brain injury. *Brain Injury*. 2013; 27: 92-102.
39. Bryson CN, Cramer RJ, Schmidt AT. Traumatic brain injury and lifetime suicidality: Applying the interpersonal-psychological theory perspective. *Death Stud*. 2017; 41(7): 399-405.
40. Achte KA, Lonnqvist J, Hillbom E. Suicides following war brain-injuries. [Acta Psychiatr Scand](#). 1971; S1-94.
41. Mann JJ, Waternaux C, Haas GL, Malone KM. Towards a clinical model of suicidal behaviour in psychiatric patients. *Am J Psy*. 1999; 156 (2): 181-189.

Living with suicidality

42. Blakey SM, Wagner HR, Naylor J, Brancu M, Lane I, Sallee M, Kimbrel NA, VA Mid-Atlantic MIRECC Workgroup, Elbogen EB. Chronic pain, TBI, and PTSD in military veterans: A link to suicidal ideation and violent impulses? *J Pain*. 2018; 19(7): 797-806.
43. Norman A. A preventable death? A family's perspective on an adult safeguarding review regarding an adult with traumatic brain injury. *J Adult Protection*. 2016; 18(6): 341-352.
44. Joiner TE, Van Orden KA, Witte TK, Selby EA, Ribeiro JD, Lewis R, Rudd MD. Main predictions of the interpersonal-psychological theory of suicidal behavior: Empirical tests in two samples of young adults. *J Abnorm Psychol*. 2009; 118(3): 634-646.
45. Solomon RL. The opponent-process theory of acquired motivation: The costs of pleasure and the benefits of pain. *Am Psychol*. 1980; 35(8): 691-712.
46. Driver K, Abed RT. Does having offspring reduce the risk of suicide in women? *Int J Psy Clin Prac*. 2004; 8(1): 25-29.
47. Chesley K, Loring-McNulty NE. Process of suicide: Perspective of the suicide attempter. *J Am Psy Nurs Assoc*. 2003; 9(2): 41-45.
48. Yamokoski CA, Scheel KR, Rogers JR. The role of affect in suicidal thoughts and behaviors. [Suicide Life Threat Behav](#)~~[Suicide Life Threat](#)~~. 2011; 41(2): 160-170.
49. Burshtein S, Dohrenwend BP, Levav I, Werbeloff N, Davidson M, Weiser M. Religiosity as a protective factor against suicidal behaviour. [Acta Psychiatr Scand](#)~~[Acta Psy Scan](#)~~. 2016; 133(6): 481-488.

Living with suicidality

50. Jones KF, Pryor J, Care-Unger C, Simpson GK. Spirituality and its relationship with positive adjustment following traumatic brain injury: a scoping review. *Brain Injury*. 2018; 32(13-14): 1612-1622.
51. Bay EH, Blow AJ, Yan XE. Interpersonal relatedness and psychological functioning following traumatic brain injury: Implications for marital and family therapists. *J Marital Fam Ther*. 2012; 38(3): 556-567.
52. Tyerman A. Vocational rehabilitation after traumatic brain injury: Models and services. *NeuroRehabil*. 2012; 31(1): 51-62.
53. Meadows LA, Kaslow NJ, Thompson MP, Jurkovic GJ. Protective factors against suicide attempt risk among African American women experiencing intimate partner violence. *Am J Comm Psychol*. 2005; 36(1-2): 109-121.
54. Lorenz LS. Discovering a new identity after brain injury. *Sociol Health Ill*. 2010; 32(6): 862-879.
55. Van Bost G, Van Damme S, Crombez G. The role of acceptance and values in quality of life in patients with an acquired brain injury: A questionnaire study. *Peer J*. 2017; 5: e3545.
56. Simpson G, Simons M, McFadyen M. The challenges of a hidden disability: Social work practice in the field of traumatic brain injury. *Australian Social Work*. 2002; 55(1), 24-37.
57. Scherzer BP, Charbonneau S, Solomon CR, Lepore F. Abstract thinking following severe traumatic brain injury. *Brain Injury*. 1993; 7(5): 411-423.
58. Dyer KF, Bell R, McCann J, Rauch R. Aggression after traumatic brain injury: Analysing socially desirable responses and the nature of aggressive traits. *Brain Injury*. 2006; 20(11): 1163-1173.

Living with suicidality

59. Simpson G, Franke B, Gillett L. Suicide prevention training outside the mental health service system: evaluation of a state-wide program in Australia for rehabilitation and disability staff in the field of traumatic brain injury. *Crisis*. 2007; 28(1): 35-43
60. Brenner L, Foster JE, Hoffberg A, Matarazzo B, Hostetter T, Signoracci G, Homaifar B, Simpson GK. Window to Hope: A randomized controlled trial of a psychological intervention for the treatment of hopelessness among veterans with moderate to severe TBI. *J Head Trauma Rehabil*. 2018; 33: E64-E73. doi: 10.1097/HTR.0000000000000351.
61. Simpson GK, Tate RL, Whiting DL, Cotter RE. Suicide prevention after traumatic brain injury: A randomised control trial of a program for the psychological treatment of hopelessness. *J Head Trauma Rehabil*; 2018; 26: 290-300. doi: 10.1097/HTR.0b013e3182225250.

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Table 1. Injury characteristics of the TBI participants (n = 19).

Variables	Data	
	N	%
Sex		
Male	18	95
Female	1	5
Injury Circumstance		
Road Traffic Accident	13	68
Fall	4	21
Assault	2	11
PTA ¹ severity		
Severe (S)	2	11
Very severe (VS)	4	21
Extremely severe (ES)	13	68
	<i>M (SD)</i>	<i>Med (IQR)</i>
Length of PTA (days)	64.6 (51.0)	60.0 (81.0)
Age at injury (years)	31.1 (11.6)	26.6 (20.0)
Years post-injury (years)	9.5 (6.7)	8.0 (9.0)

¹Post-Traumatic Amnesia: S = 1-7 days, VS = 8-28 days, ES = 28+ days

Table 2. Psychosocial demographics of TBI participants (n = 19).

Variables	Data	
	<i>Pre-injury</i>	<i>Post-injury</i>
	<i>n (%)</i>	<i>n (%)</i>
Marital status		
Married/ defacto	3 (16)	3 (16)
Single	11 (58)	11 (58)
Separated/ divorced	3 (16)	5 (26)
Unknown	2 (11)	0 (0)
Living		
Alone	15 (79)	10 (53)
Spouse	4 (21)	3 (16)
Parents	0 (0)	3 (16)
Attendant care/ nursing staff	0 (0)	2 (10)
Other	0 (0)	1 (5)
Vocation		
Professional/ managerial	1 (5)	0 (0)
Unskilled/ semi-skilled	7 (37)	0 (0)
Skilled labour	6 (32)	2 (11)
Clerical skills	2 (10)	0 (0)
Student	3 (16)	0 (0)
Supported work	0 (0)	1 (5)
Volunteer	0 (0)	1 (5)
In rehabilitation	0 (0)	2 (11)
Avocational	0 (0)	13 (68)
Activity status		
Full-time	12 (63)	4 (21)
Part-time	4 (21)	7 (37)
Unemployed	3 (16)	7 (37)
Casual	0 (0)	1 (5)

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Table 3. Clinical demographics of TBI participants (*n* = 19).

Variables	Data	
	<i>N</i>	%
Current alcohol use		
Not at all	8	42
Once a month or less than	8	42
Once a week or weekends	2	11
A few times a week	1	5
Pre-injury alcohol problem		
No	15	79
Yes	4	21
Post-injury alcohol problem		
No	16	84
Yes	3	16
Current drug use		
Not at all	10	53
Once a month or less than	3	16
A few times a week	5	26
Daily	1	5
Pre-injury drug problem		
No	14	74
Yes	5	26
Post-injury drug problem ²		
No	14	74
Yes	5	26
Psychiatric problem (lifetime) ³		
None diagnosed	5	
Schizophrenia	3	
Depression/ suicidality	13	
Personality disorder	1	
Pre-injury psychiatric problem		
No	17	90
Yes	2	10
Post-injury psychiatric problem		
No	3	16

Yes

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² A participant was classified clinically as having a problem with either alcohol or drug use if there was evidence of significant disruption to the person's life as a consequence of the use such as incurring legal charges, medical condition, loss of job due to intoxication, relationship breakdown. A classification of a problem with either alcohol or drug use was not solely based on the quantity of current use.

³ Some participants had more than one diagnosis.

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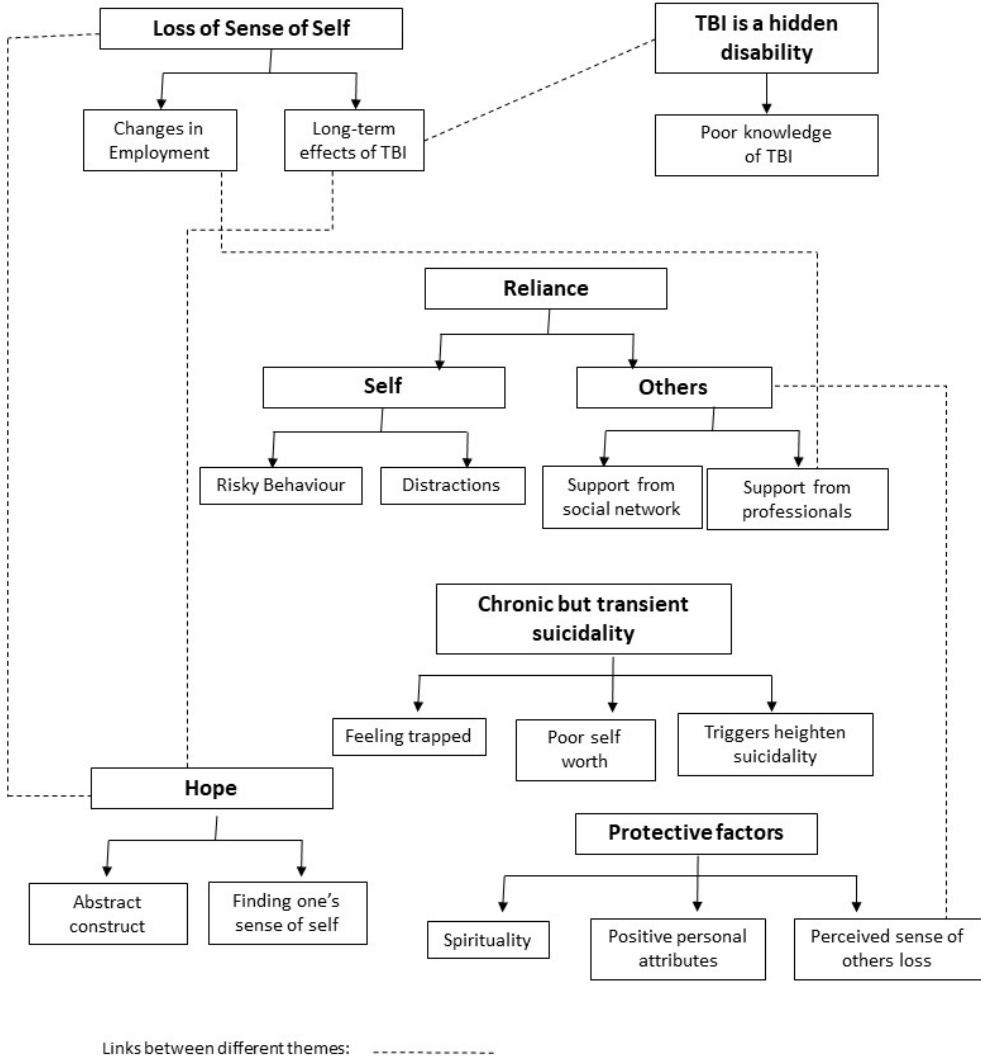


Figure 1: a thematic map of overarching themes and sub themes regarding experiences of living with suicidality following TBI

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